



# **Research for Health: The Power of Advocacy**

**Mary Woolley**

**Research!America**

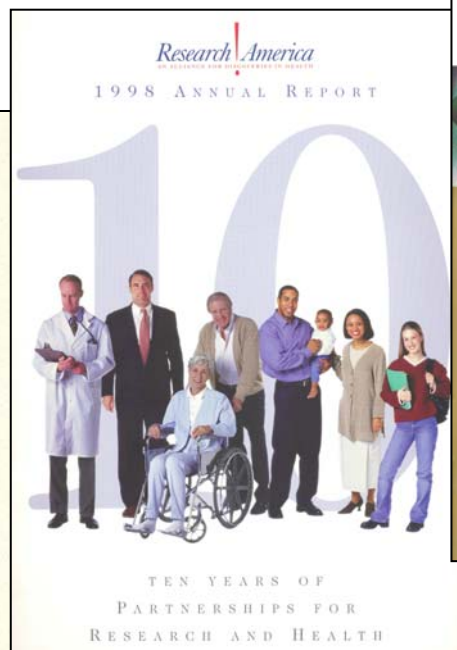
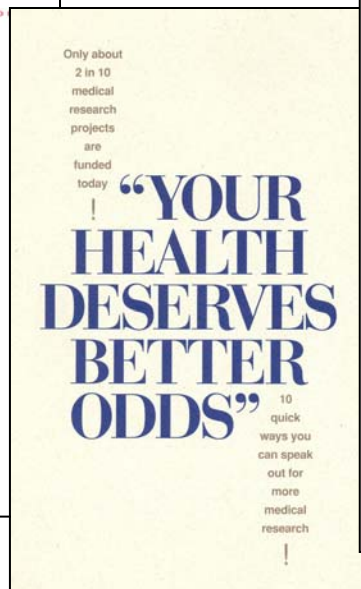
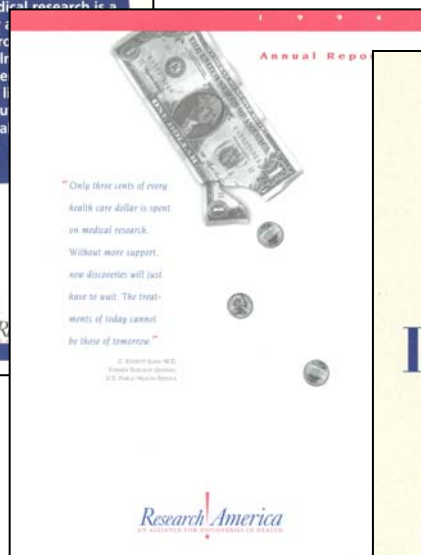
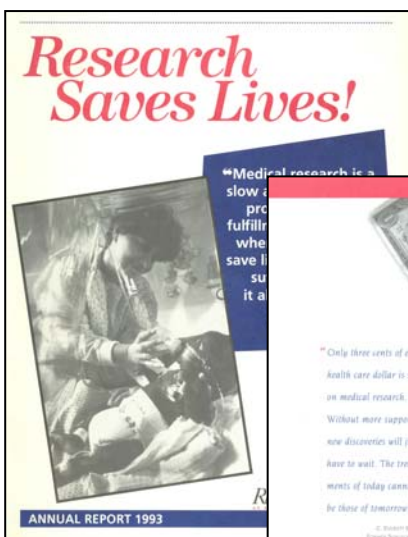
**January 14, 2005**

**The Health Legacy Partnership  
Washington, D.C.**

# Research | America

AN ALLIANCE FOR DISCOVERIES IN HEALTH®

## 16 Years of Putting Research on the Public Agenda





## **Nonprofit alliance with nearly 500 members including:**

- **Academia, hospitals, independent research institutions**
- **Professional and science societies**
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- **Voluntary health organizations**
- **Trade associations**
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# Research!America's Goals

- **Ensure that the public hears about research and its benefits**
- **Achieve more funding for medical and health research**
- **Advocate a policy climate that stimulates rather than impedes research**
- **Work with others to advocate for medical and health research**

# **Selected Research!America Accomplishments**

- **Leadership in doubling the National Institutes of Health budget (1999-2003)**
- **Leadership in public opinion polling on medical and health research, including clinical research public health and health services research**
- **Leadership in message development for research advocacy**
- **Leadership internationally to spur advocacy for research**

# Bringing Research Closer to Home

- **Media/Science Forums**
- **Leadership Forums**
- **Advocacy Workshops**
- **Editorial Board Visits**
- **Public-Opinion Polls**
- **Advocacy Tools**



# **Research!America Polls**

**Commissioning public opinion polls on  
research issues for 13 years**

- **National Polls**
- **State-Based Polls**
- **Issue-Specific Polls**

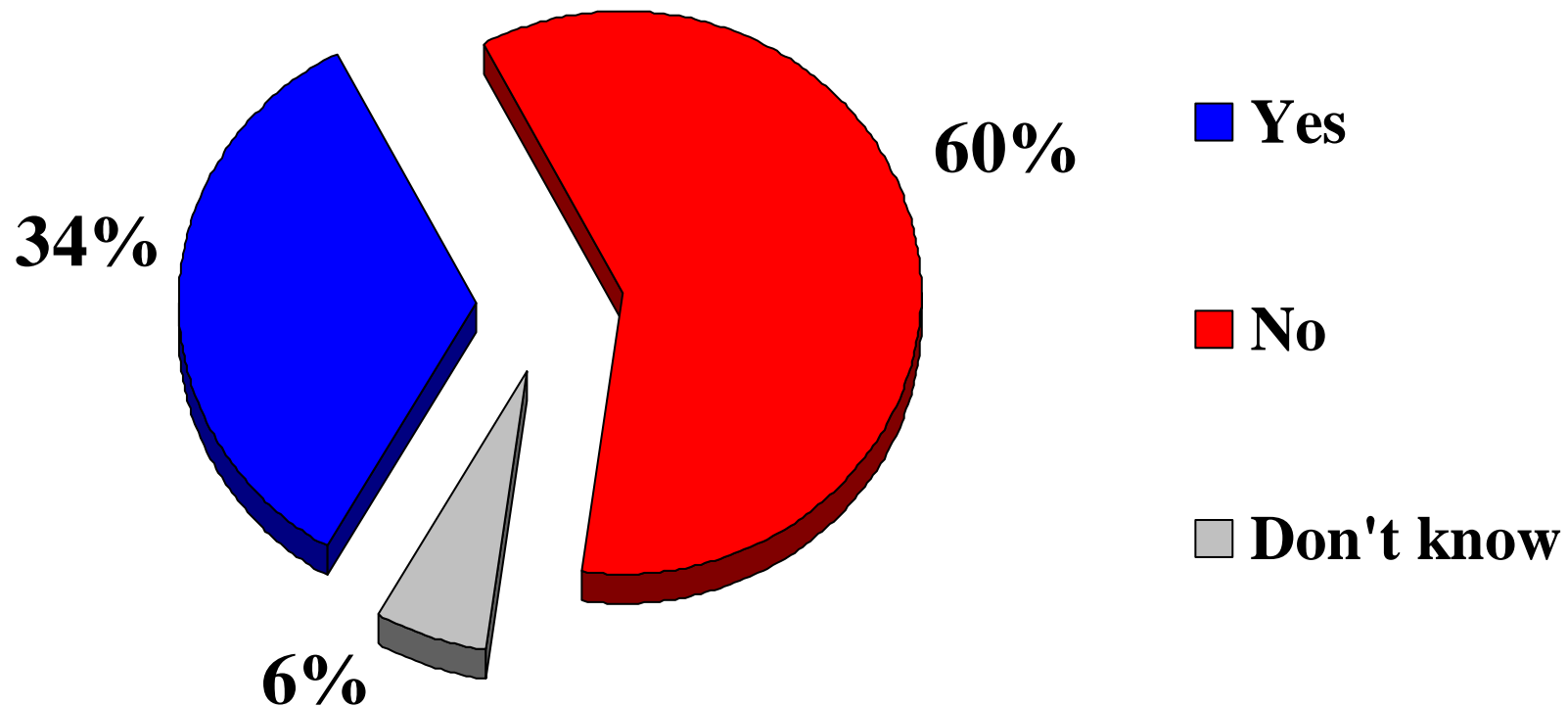
# Typical Survey Methodology

- ❖ Telephone (random-digit dialing) polls are conducted with a sample size of 800-1000 adults (age 18+) and a maximum theoretical sampling error of +/- 3.5 percent. Data are demographically representative of adult U.S. residents (state or national).
- ❖ Online polls are conducted with a sample size of 1000-2000 adults and sampling error of +/-3.1 percent. The data is weighted in two stages to ensure accurate representation of the U.S. adult population.
  1. Figures for age, sex, race, education, and income is weighted where necessary to bring them into line with population demographics.
  2. “Propensity score” weighting is also used to adjust for respondents’ propensity to be online.



# Americans Say U.S. Health Care Not the Best

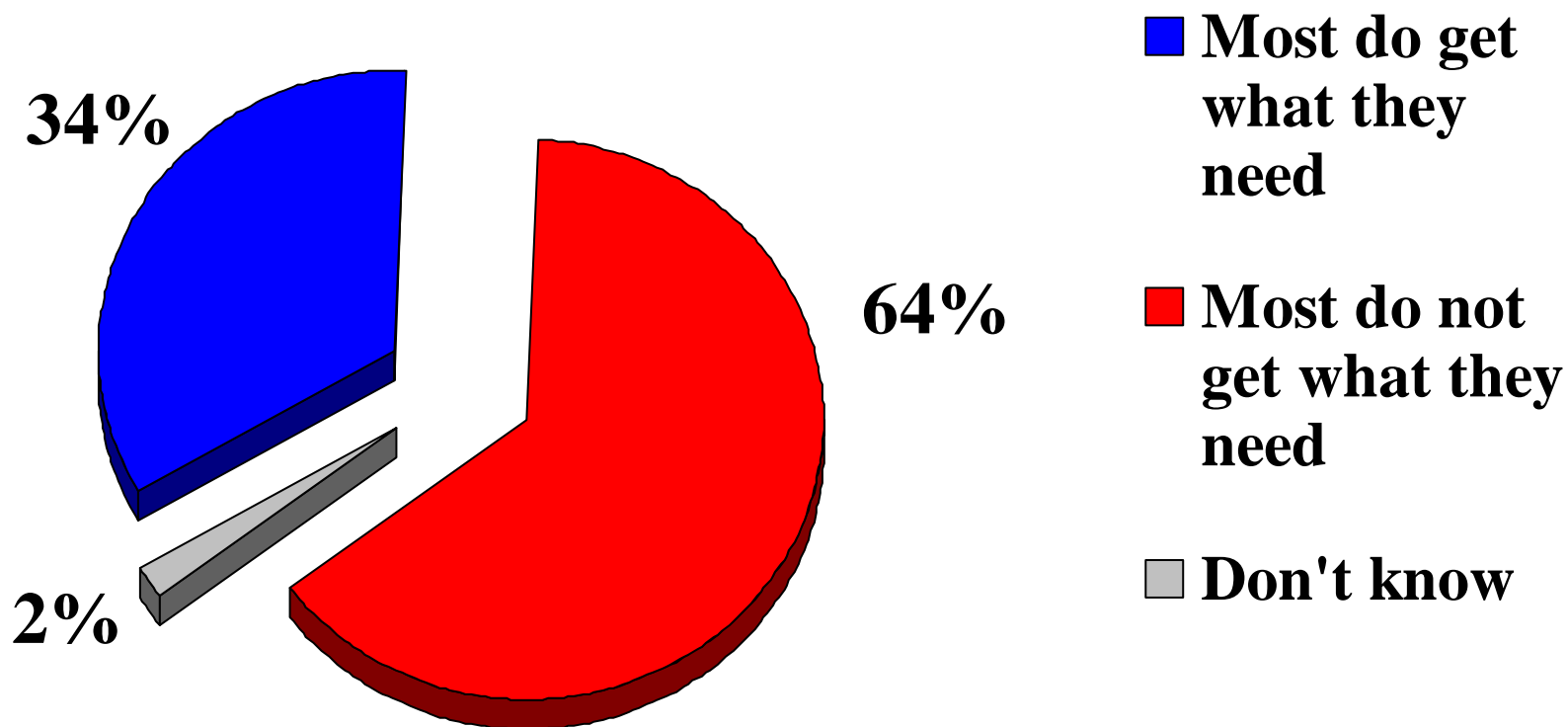
Do you believe that the United States has the best health care system in the world?



Source: National Survey, 2005  
Charlton Research Company for Research!America

# Americans Do Not Get Health Care They Need

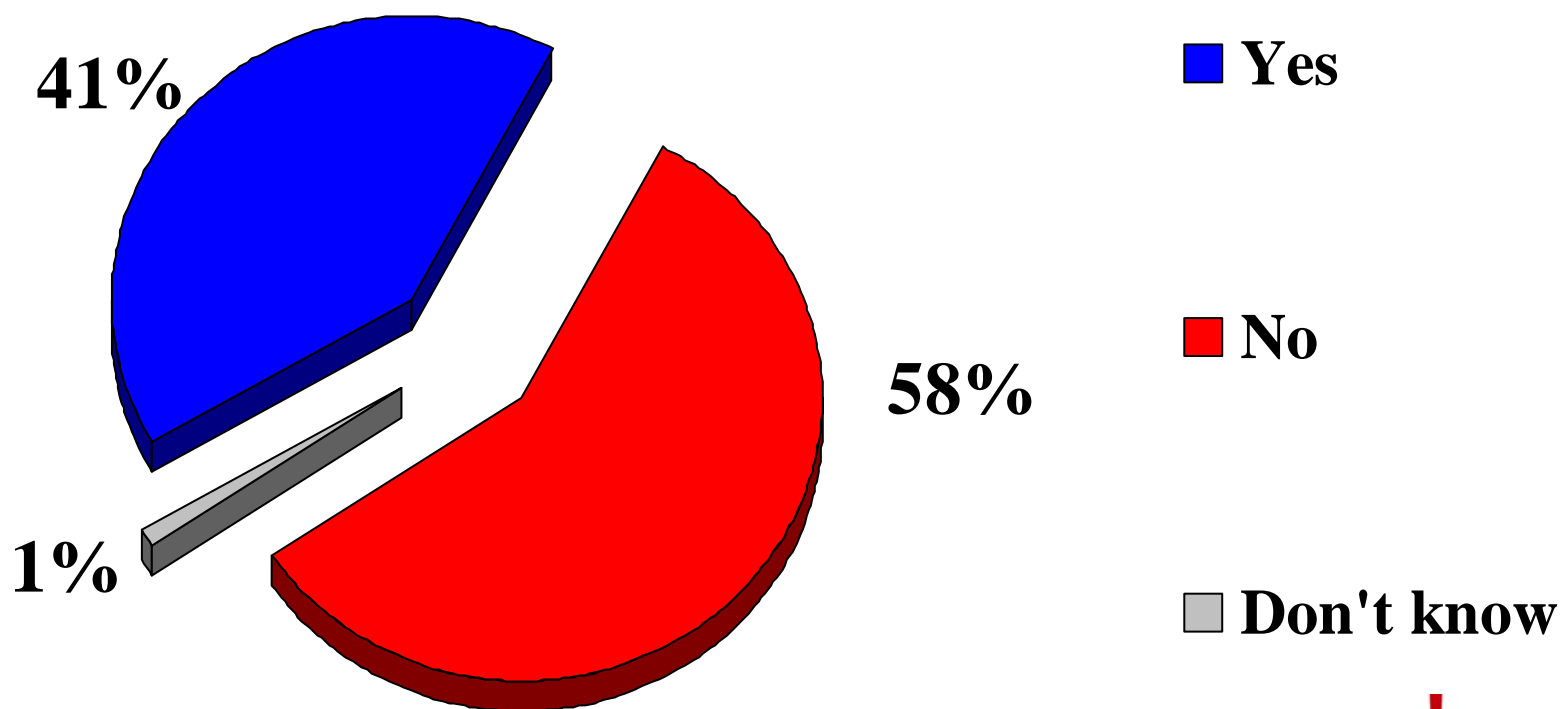
Do you think that most people in this country get the health and medical care they need or not?



Source: National Survey, 2005  
Charlton Research Company for Research!America

# Medical Errors Affect Many Americans

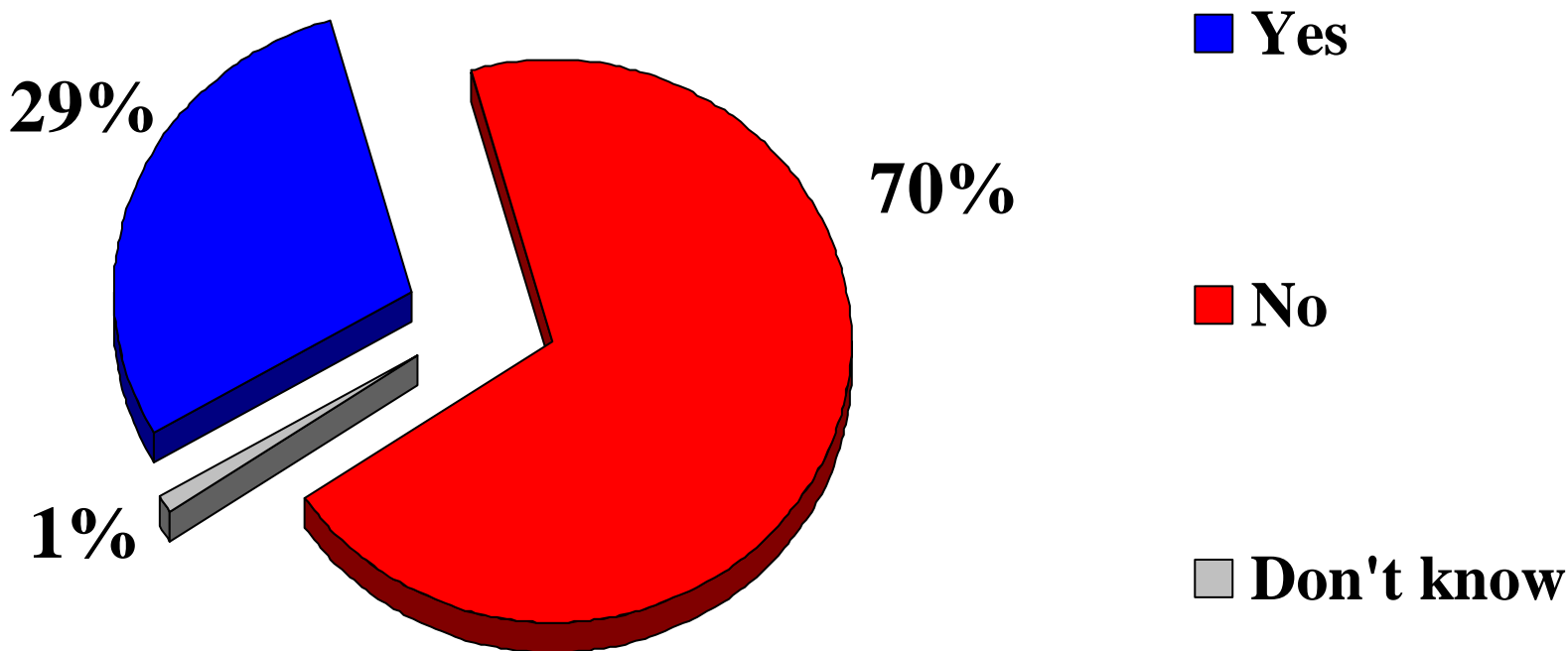
Sometimes when people receive health care, mistakes are made that result in serious harm such as death, disability, or additional or prolonged treatment. These are called medical errors. Some of these errors are preventable, while others may not be. Have you or someone you know experienced a medical error?



Source: National Survey, 2005  
Charlton Research Company for Research!America

# Majority of Americans Don't Feel They Get Unnecessary Care

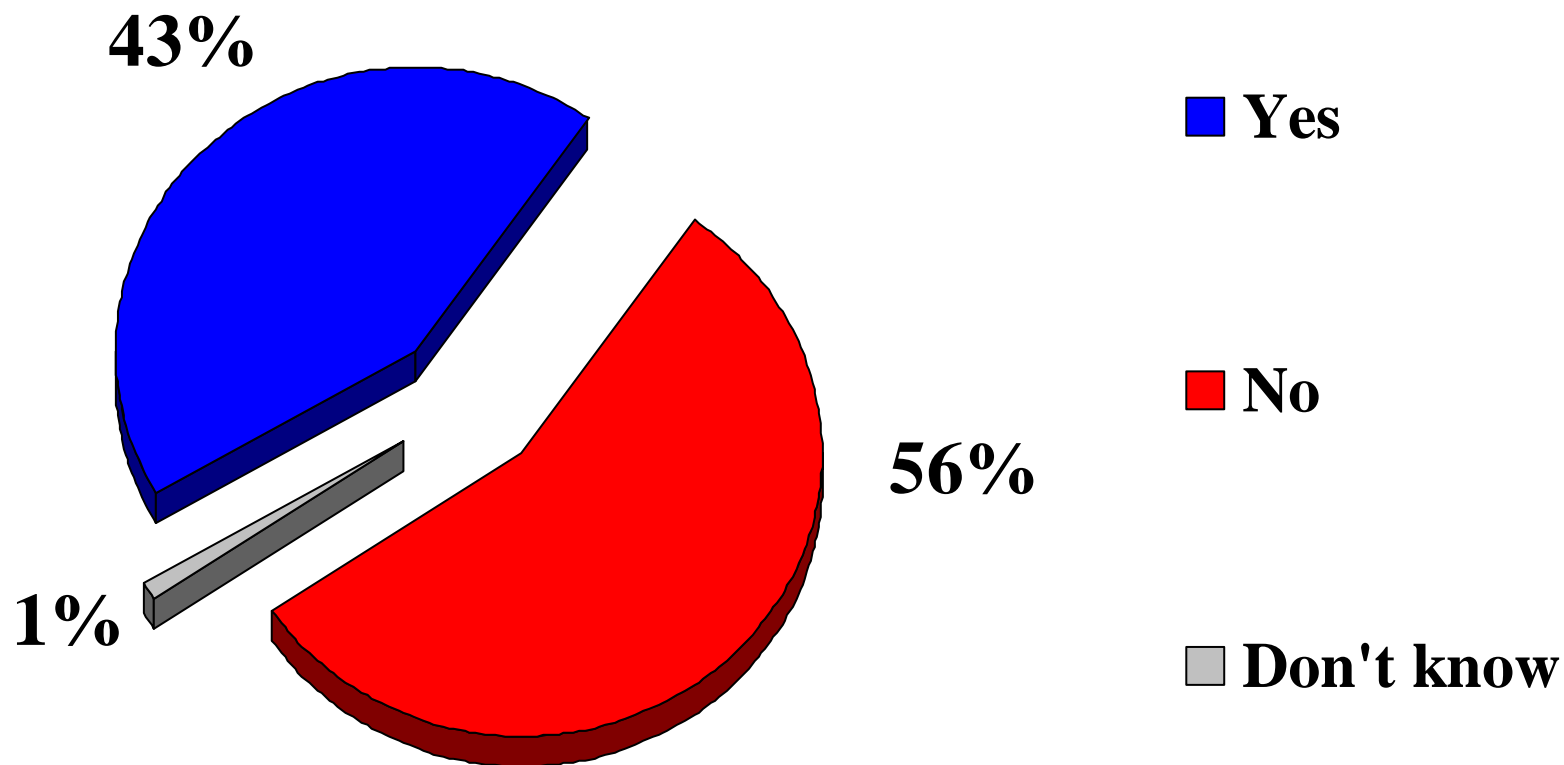
Can you think of a time when you felt that you or a family member received unnecessary health care or treatment?



Source: National Survey, 2005  
Charlton Research Company for Research!America

# Americans Feel They Do *Not* Always Get Necessary Care

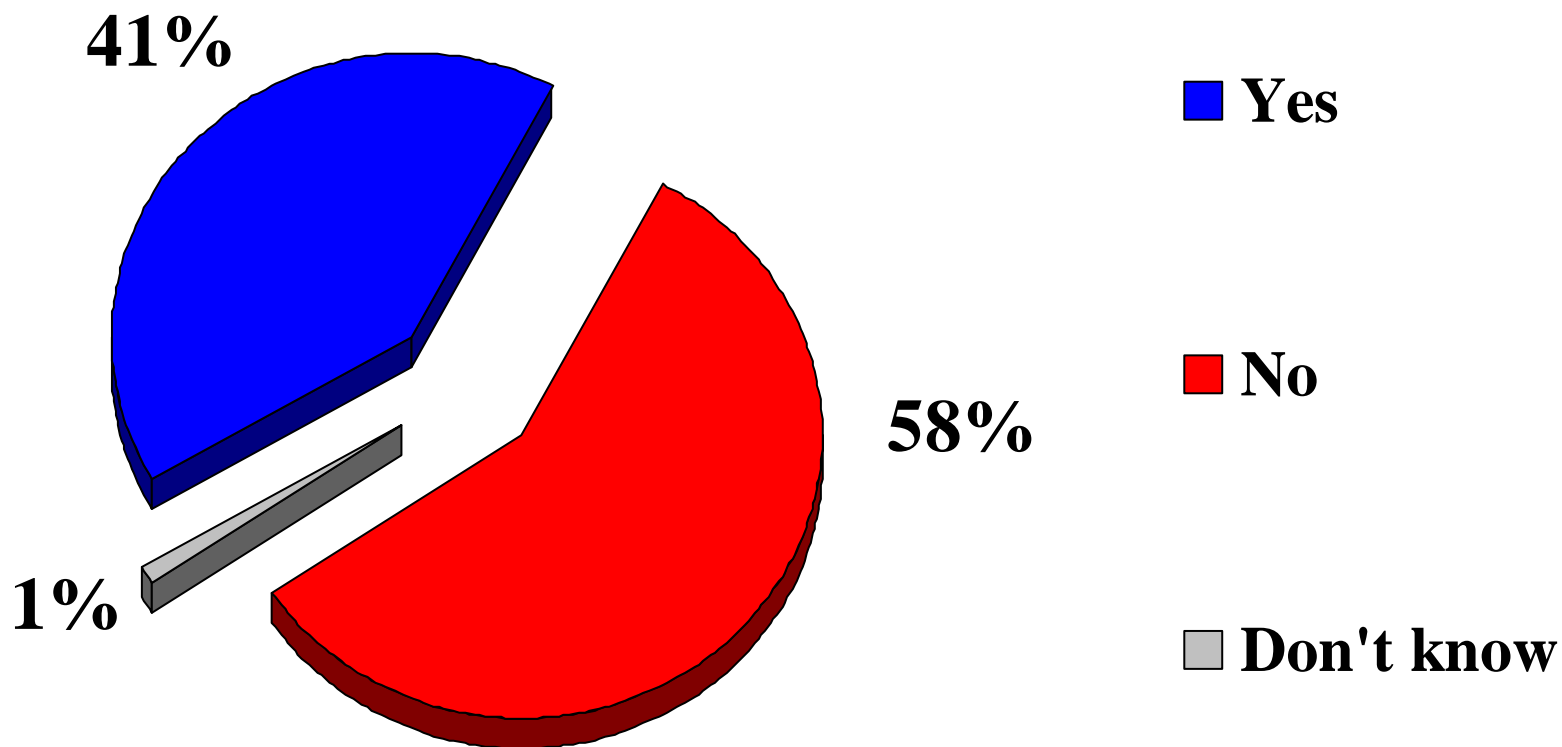
Can you think of a time when you felt that you or a family member didn't get the health care or treatment that was needed?



Source: National Survey, 2005  
Charlton Research Company for Research!America

# Many Americans Think They Got the *Wrong* Care

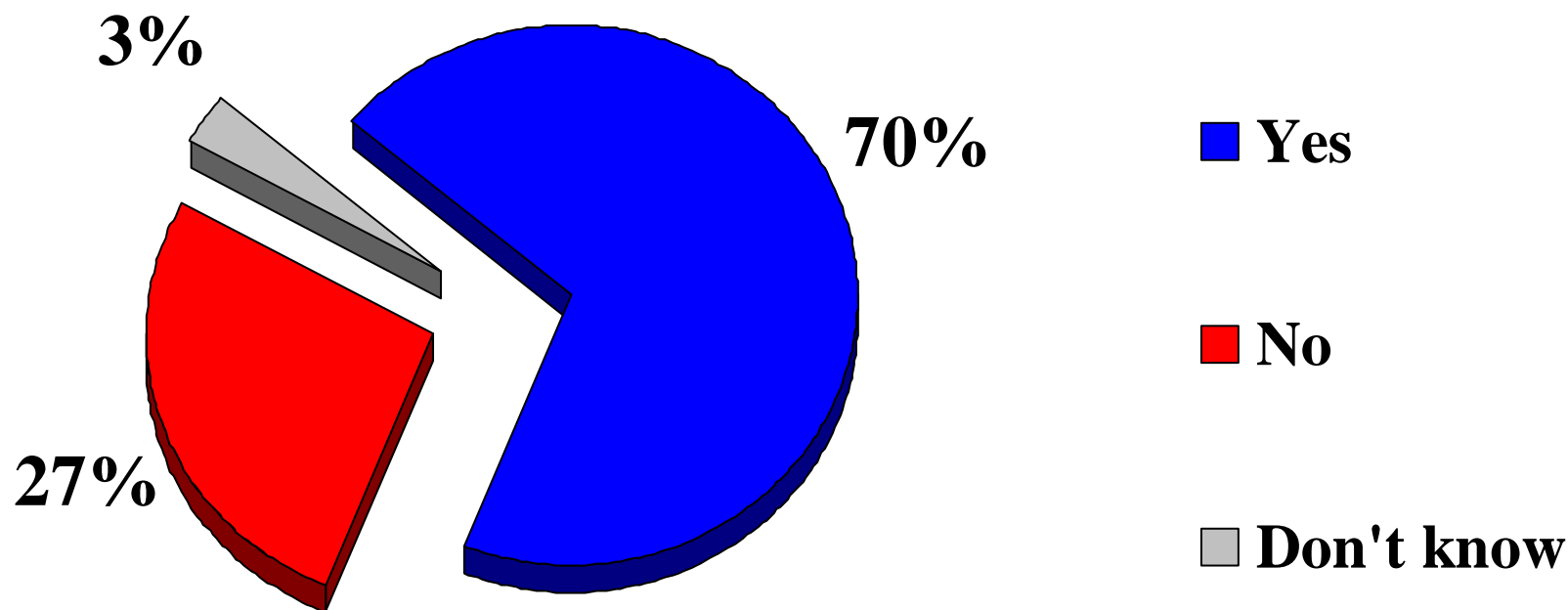
Can you think of a time when you felt that you or a family member got what turned out to be the wrong health care or treatment?



Source: National Survey, 2005  
Charlton Research Company for Research!America

# Americans Believe Health Care Is Based On Research

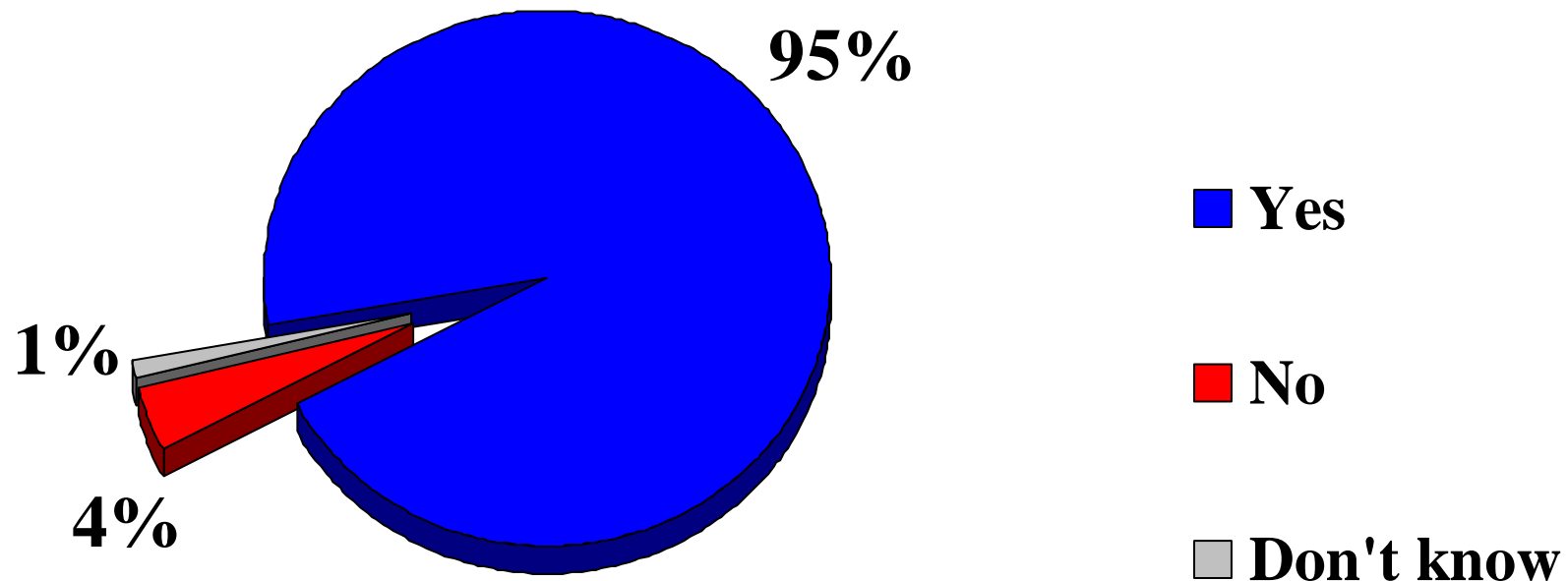
Do you believe that the health care services you receive are based on the best and most recent research available?



Source: National Survey, 2005  
Charlton Research Company for Research!America

# Americans Believe Health Care *Should Be* Based On Best Research

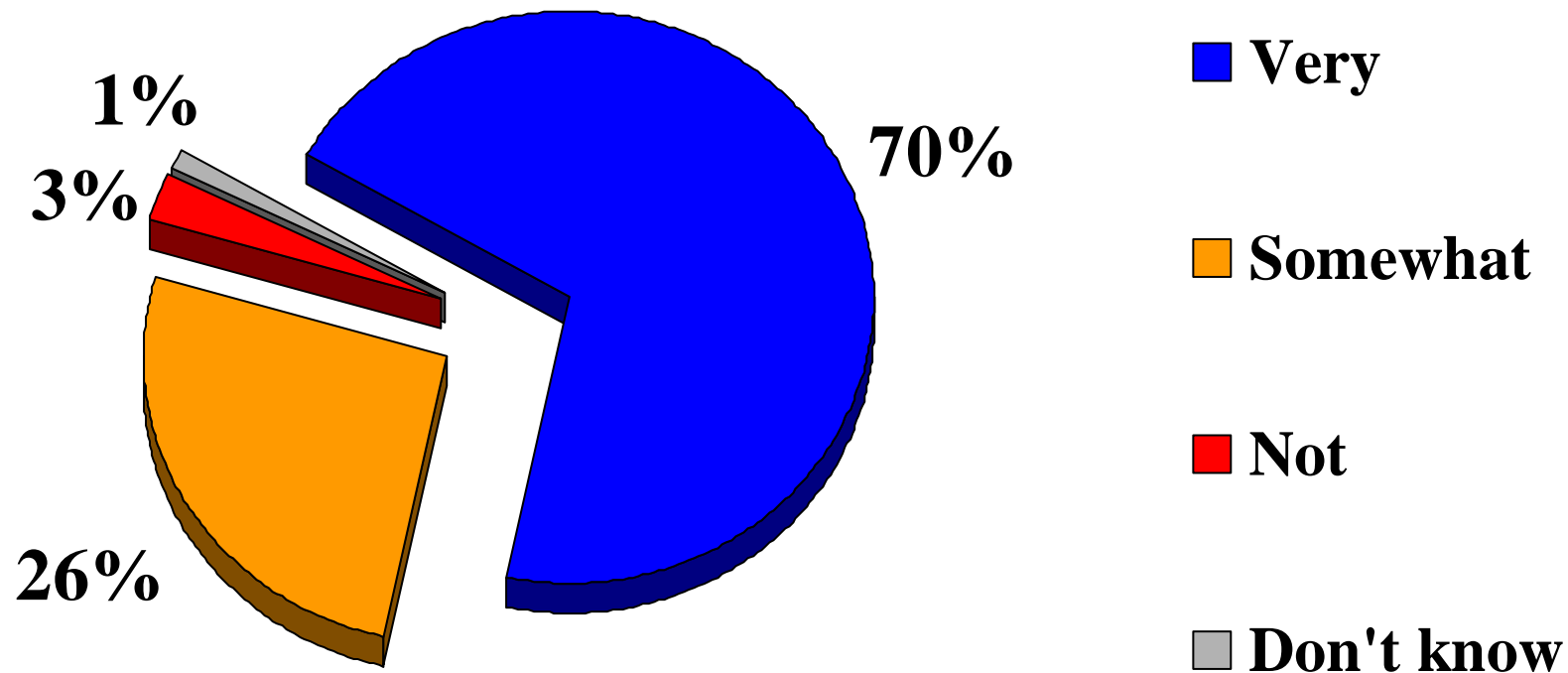
Do you believe that the health care services you receive *should be* based on the best and most recent research available?



Source: National Survey, 2005  
Charlton Research Company for Research!America

# Americans Think Investment in Research Important for Health Care

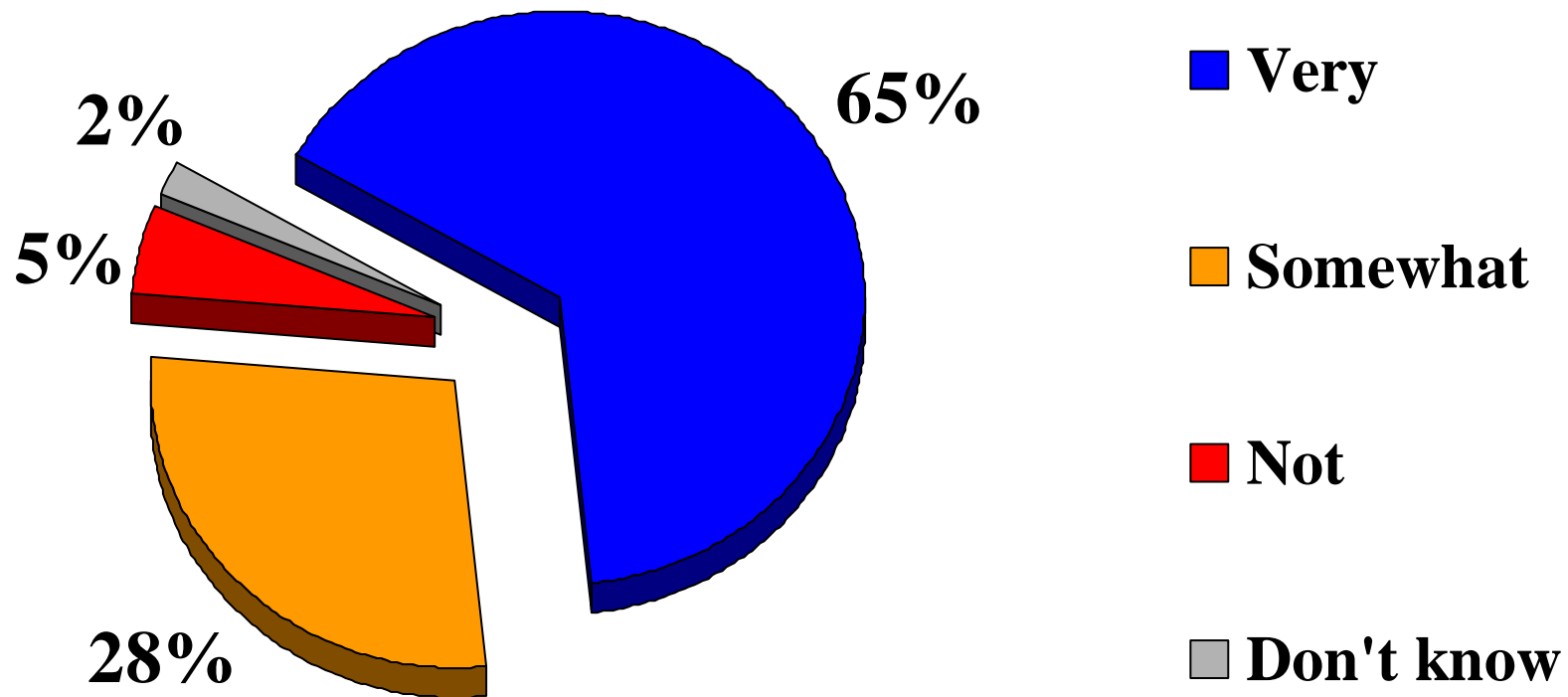
How important do you think it is that we invest in more research to assure that there is a solid scientific base for healthcare?



Source: National Survey, 2005  
Charlton Research Company for Research!America

# U.S. Investment in Health Services Research Is Very Important

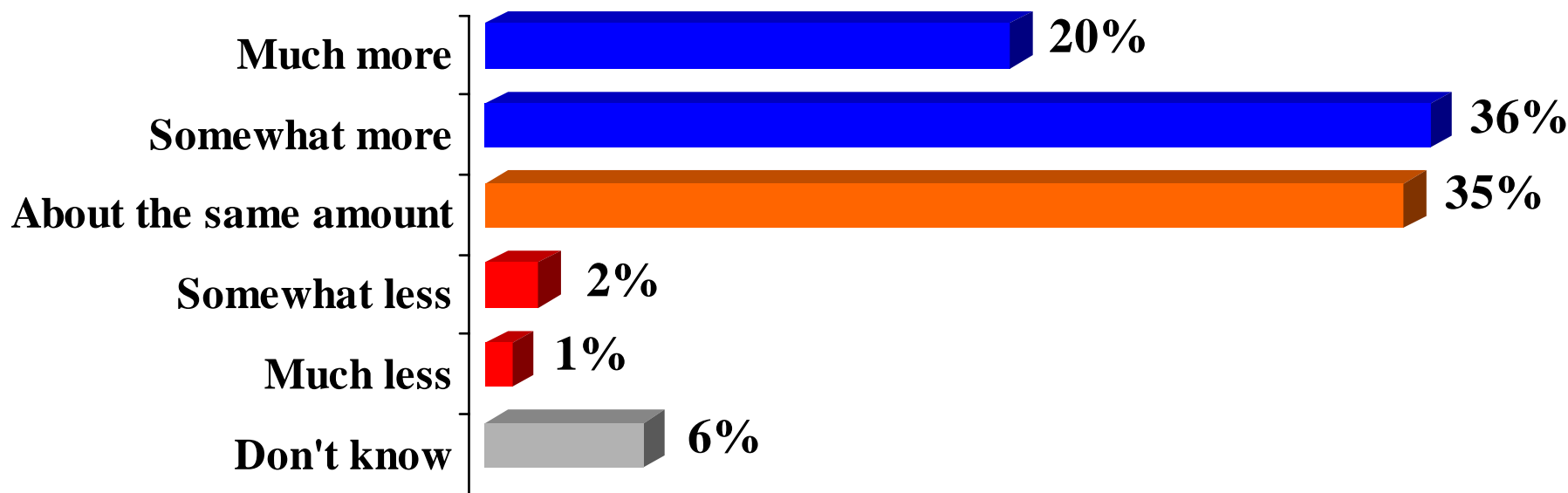
A type of research called health services research seeks to translate discoveries from research into medical practice. How important do you think it is for the United States to invest in health services research?



Source: National Survey, 2005  
Charlton Research Company for Research!America

# Americans Want More Spent on Health Services Research

Currently, much less than one cent out of each health dollar spent in the U.S. is spent on research that helps translate discoveries into medical practice. How much of each health dollar do you think we **SHOULD** spend?



Source: National Survey, 2005  
Charlton Research Company for Research!America

# “Dollars & Sense”



- The golf industry has a revenue of \$2 billion a year for clubs and golf balls alone.

- That amount would fund the Agency for Healthcare Research and Quality for 6 years!

**“Taking Charge of Your Own Health”**  
**PARADE/**  
**Research!America Poll**  
**September 19, 2004**

# PARADE

A Practical Guide

## Taking Our Pulse

The PARADE/Research!America Health Poll

### Taking Charge Of Our Own Health

This poll—the third in a series—takes a look at topics covered in this special issue, which focuses on the increasing emphasis on the individual in medical treatment and the growing involvement of patients in their care. The poll was conducted by the Charlton Research Co. and commissioned by PARADE and Research!America, a nonprofit public education and advocacy group. Here are some of the results:

#### Personalized Medicine

Would you be willing to contribute a sample of your DNA to a national databank to be used only for health-related research?

48% said “yes”;  
 42% said “no”;  
 10% don’t know.

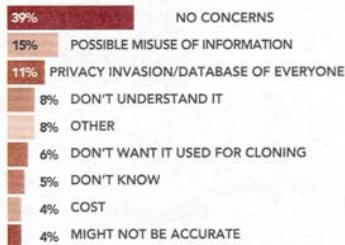
Would you want to be genetically tested to determine which medications might be most effective and safest for you?

62% said “yes”;  
 34% said “no”;  
 4% don’t know.

Would you be willing to pay more for genetically personalized health care?

34% said “yes”;  
 57% said “no”;  
 9% don’t know.

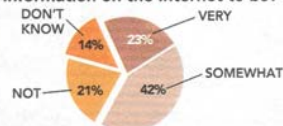
Researchers recently finished mapping the human genome and now can analyze one’s complete genetic makeup. What concerns, if any, do you have about genetic testing?



Our poll of 1000 people, representing a cross-section of Americans, has a sampling error of  $\pm 3.1\%$ .

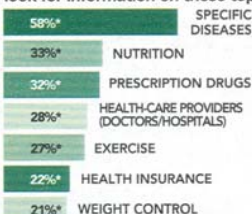
#### Online Medicine

How useful have you found health information on the Internet to be?



Do you belong to an online support group for a specific medical condition, such as arthritis, cancer or diabetes?  
 3% said “yes”; 97% said “no.”

Have you ever used the Internet to look for information on these topics?

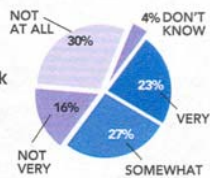


\* Percent responding “yes.”

Have you ever used e-mail to communicate with your doctor or health-care provider? Has your doctor ever suggested you visit a Web site for additional information?  
 One in 10 respondents answered “yes” to each question.

Have you ever asked your doctor or another health professional to let you see your medical records?  
 39% said “yes”; 61% said “no.”

How useful would it be if you could look at your personal medical records online?



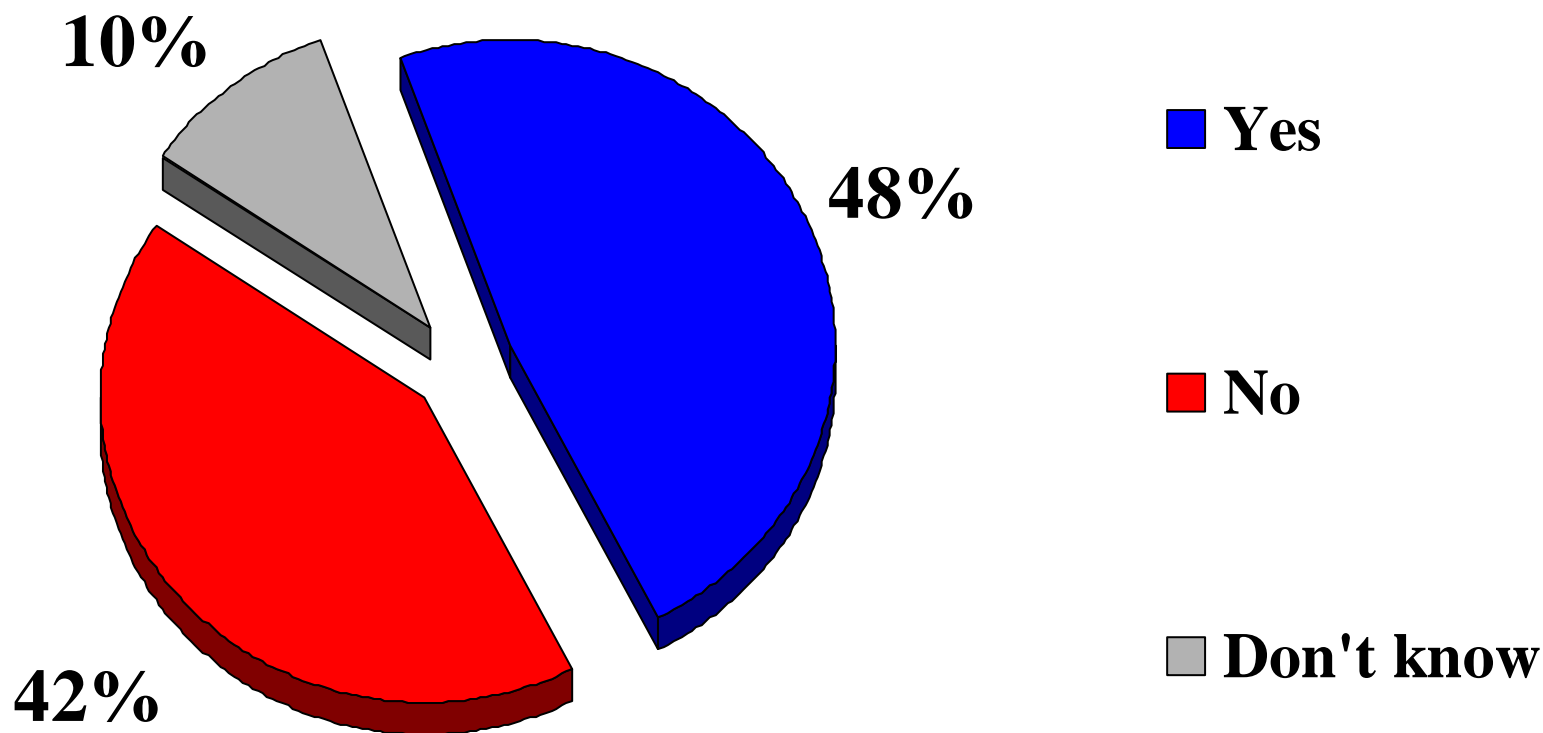
The newly engaged former star of TV's *Dawson's Creek* talks about her budding film career

## She's All Grown Up

In Step With **Katie Holmes** By James Brady

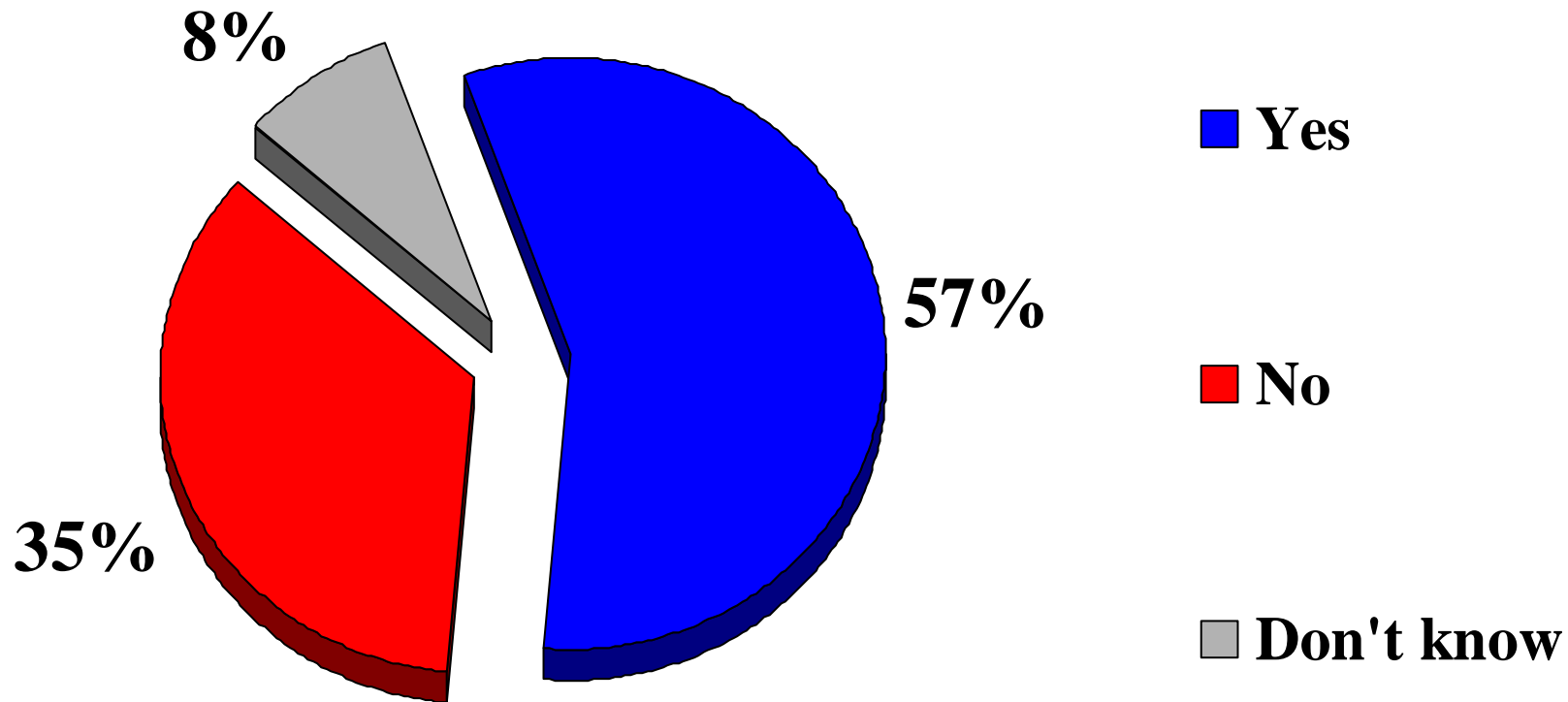
# Many Americans Willing to Contribute DNA for Research

Would you be willing to contribute a sample of your DNA to a national databank to be used *only* for health related research?



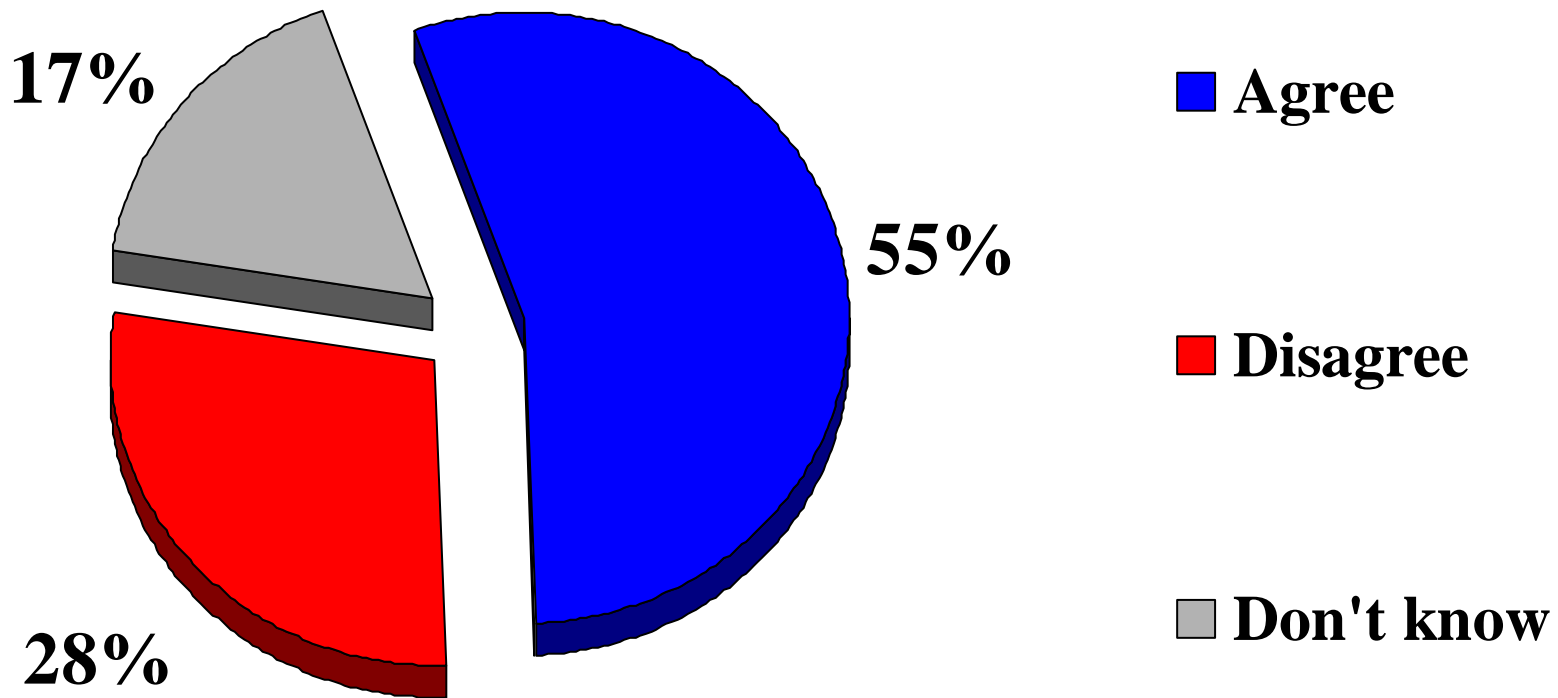
# Americans Willing to be Genetically Tested

Researchers recently completed mapping the human genome and can now analyze an individual's complete genetic makeup. Would you be willing to be genetically tested to help doctors diagnose and prevent disease?



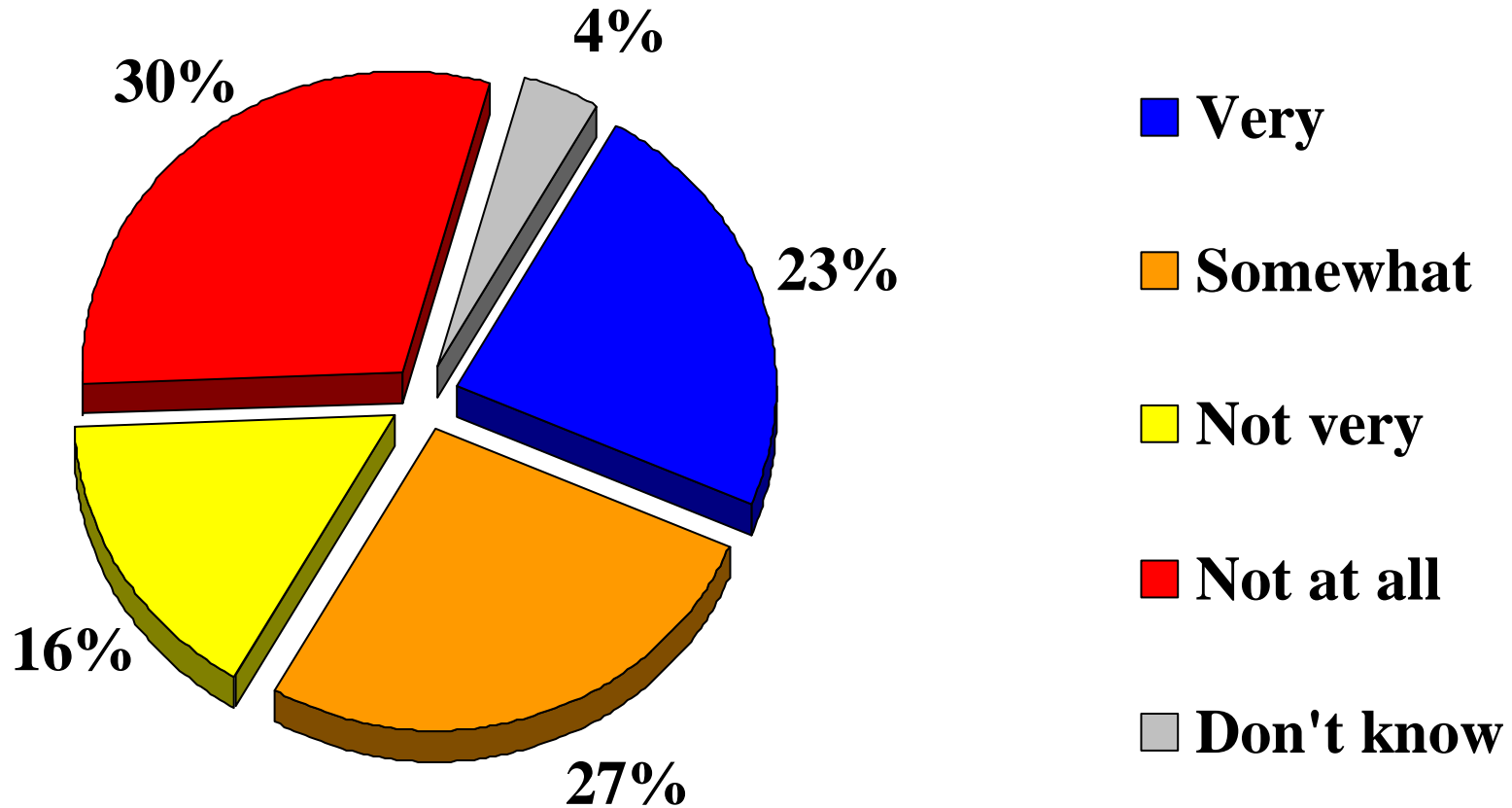
# Internet Helps Many Americans Understand Own Health

Do you agree or disagree that health information on the internet has improved your understanding of your overall health?



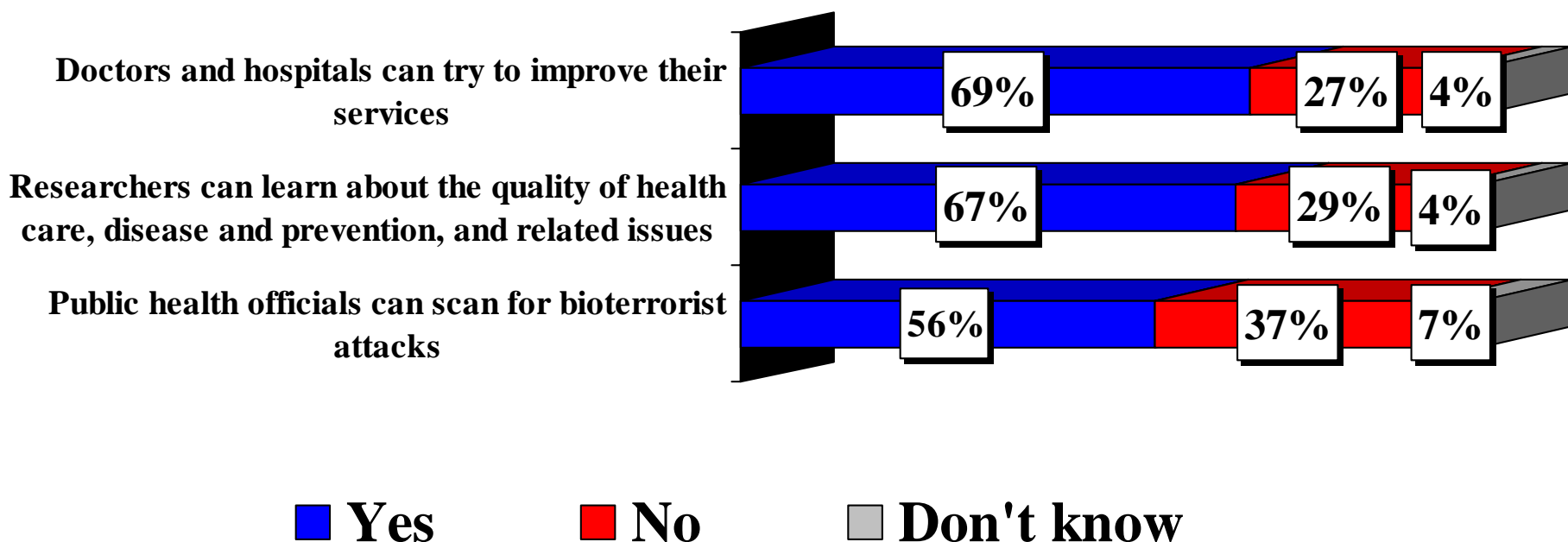
# Americans Divided on Usefulness of Online Medical Records

How useful would it be if you could look at your personal medical records online?



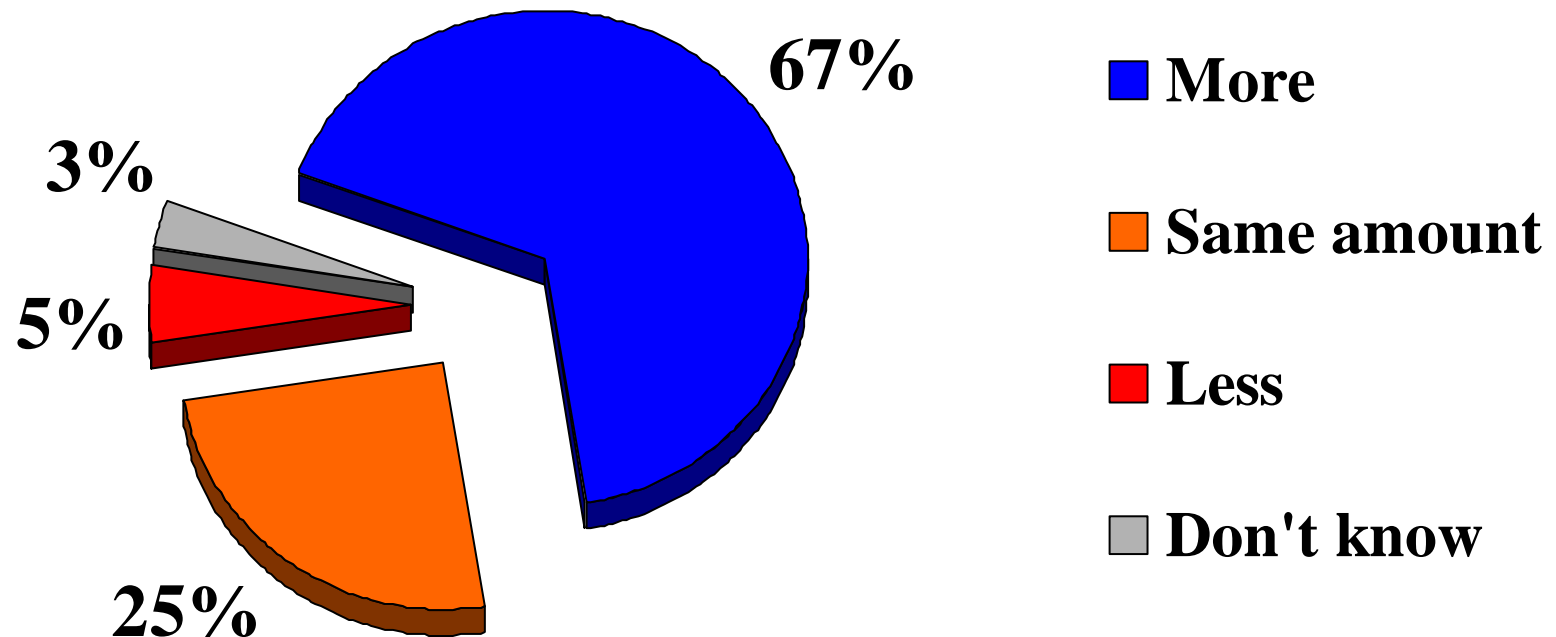
# Americans Willing to Share Medical Information

Assuming that there is no way anyone will have access to your identity, would you be willing to release your health information so that...



# Americans Want More Information About Medical Research

Would you like to see more, less, or about the same amount of information as there is in newspapers, magazines, or on television about scientific and medical research?



Source: National Survey, 2005  
Charlton Research Company for Research!America

# Public Trust in Sources of Research Information

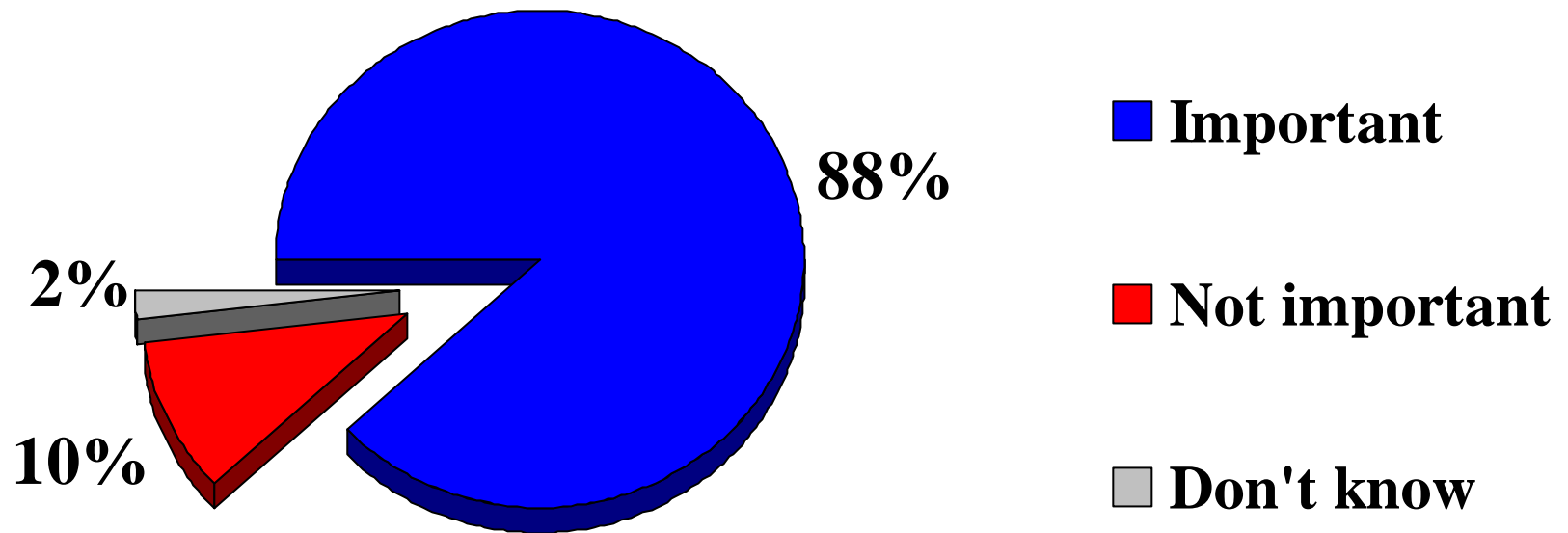
As you are probably aware, there are many sources of information about medical and health research issues. For each of these sources, I'd like you to tell me how trustworthy you think the information they provide is? (*% responses trustworthy*)

Nurses	96%
Pharmacists	95%
Your Physician	95%
Medical Schools and Teaching Hospitals	93%
Your Dentist	92%
Voluntary Health Agencies	89%
Government Agencies (such as NIH and CDC)	83%
The Internet	56%
Media Sources	55%
Pharmaceutical Companies	53%

Source: National Survey, 2005  
Charlton Research Company for Research!America

# Important to Eliminate Health Disparities

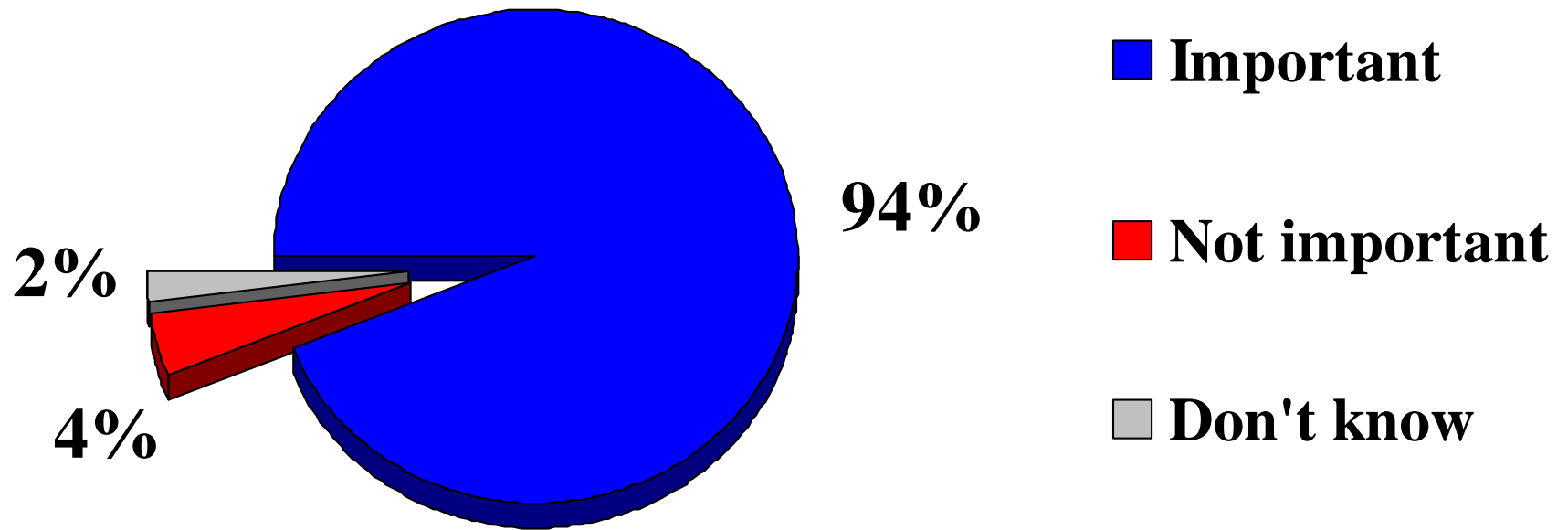
Studies show that certain health problems such as diabetes, heart disease and infant mortality happen more often among citizens with lower incomes and minorities. How important do you feel it is to conduct medical or health research to understand and eliminate these differences?



Source: "Taking Our Pulse: The PARADE/Research!America Health Poll" conducted by Charlton Research Company, 2004

# Research Important to U.S. Economy

How important do you think medical and health research is to the US economy?



Source: National Survey, 2005  
Charlton Research Company for Research!America

# Investment in research saves lives and money

## Lasker/Funding First

The medical and health  
manuscript policy program of the  
Mary Woodard Lasker Charitable Trust  
[www.fundingfirst.org](http://www.fundingfirst.org)  
[www.laskerfoundation.org](http://www.laskerfoundation.org)

*If you think research is expensive, try disease.*  
— Mary Lasker 2001-2006

facts about:

## Research: An Economic Driver

### Today:

- Research is the supply side of medical and scientific innovation. Biotechnology, pharmaceuticals—such as biotechnology, medical device and pharmaceutical—are rooted in research and development (R&D) and require new discoveries to remain competitive.\*
- More than 685,000 people in the United States are currently employed in the biosciences. The Bureau of Labor Statistics projects that employment in the biosciences will grow at an annual rate 13 percent greater than the rate of overall employment.\*\*
- A \$1 increase in public basic science funding stimulates \$3.15 in pharmaceutical investment.\*\*\*

SOURCE: NATIONAL SCIENCE FOUNDATION, NATIONAL RESEARCH AND DEVELOPMENT SURVEY, 2004; NATIONAL INSTITUTE OF MEDICINE, NATIONAL RESEARCH AND DEVELOPMENT SURVEY, 2004

\*BIOLOGICAL AND MEDICAL RESEARCH: THE NATIONAL INSTITUTE OF MEDICINE, NATIONAL RESEARCH AND DEVELOPMENT SURVEY, 2004

\*\*BUREAU OF LABOR STATISTICS, BUREAU OF ECONOMIC ANALYSIS, NATIONAL RESEARCH AND DEVELOPMENT SURVEY, 2004

### SAVING LIVES SAVING MONEY

#### HOW RESEARCH SAVES LIVES:

- Death rates from the nation's number one killer, heart disease, have been cut by more than 60 percent in the past 50 years.
- Gleevec represents a new class of anti-cancer drugs with minimal side effects. The basic scientific concepts and the cancer-causing molecule that Gleevec targets were discovered 20 years ago by scientists funded by the National Institutes of Health. Private investment created the drug. This success story exemplifies the need for public/private partnerships throughout the R&D continuum.

SOURCE: CENTERS FOR DISEASE CONTROL AND PREVENTION, [www.cdc.gov](http://www.cdc.gov); NATIONAL INSTITUTE OF HEALTH, [www.nih.gov](http://www.nih.gov)

#### HOW RESEARCH SAVES MONEY:

- Economists estimate a \$7 return to the economy for every \$1 spent on technological innovation in heart attack care.\*
- In compensating the families of the 9/11 victims, the U.S. government estimated the economic value of a working adult's life at about \$3 million. Health economists estimate that the thousands of lives saved by preventing and treating heart disease and stroke from 1971 to 1998 were worth \$1.1 billion each year. (That represents one-fifth of the U.S. gross domestic product (GDP) which averaged \$5.5 billion annually during the same period of time.)\*\*

SOURCE: "HEALTH CARE AND ECONOMIC LIFE," TECHNOLOGICAL CHANGE AND ECONOMIC ACTIVITY, HEALTH CARE, 2001, 2001, 2001

\*\*JOURNAL OF HEALTH ECONOMICS, 20, 2001, 2001

### Research important to U.S. economy

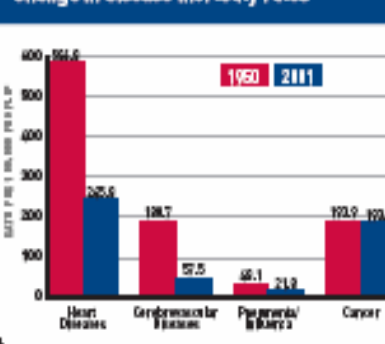
How important do you think medical and health research is to the U.S. economy?

- Important
- Not important
- Don't know



SOURCE: "HEALTH CARE AND ECONOMIC LIFE," TECHNOLOGICAL CHANGE AND ECONOMIC ACTIVITY, HEALTH CARE, 2001, 2001, 2001

### Change in disease mortality rates



SOURCE: NATIONAL CENTER FOR HEALTH STATISTICS, NATIONAL MORTALITY SURVEY, 1950-2011; NATIONAL CENTER FOR HEALTH STATISTICS, NATIONAL MORTALITY SURVEY, 1950-2011; NATIONAL CENTER FOR HEALTH STATISTICS, NATIONAL MORTALITY SURVEY, 1950-2011

*Cancer and diabetes cost more in one year (\$322 billion) than the United States has invested in the National Institutes of Health (\$279 billion) since its founding 117 years ago.*

facts about:

## Research: An Economic Driver

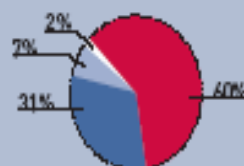


### U.S. should be world leader in medical and health research

How important do you think it is to that the U.S. maintain its role as a world leader in medical and health research?

SOURCE: "HEALTH CARE AND ECONOMIC LIFE," TECHNOLOGICAL CHANGE AND ECONOMIC ACTIVITY, HEALTH CARE, 2001, 2001, 2001

- Very
- Somewhat
- Not
- Don't know



### Hope for the Future:

*Our ability to lead in 2025 will be a function of current decisions. Increasing our investment in science and discovery is a sound and responsible national security policy. No other federal expenditure will do more to create jobs, grow wealth, strengthen our world leadership, protect our environment, promote better education or ensure better health for the country. We must make the commitment to increase our investment now.*

FRANK BRUNSWICK, DIRECTOR, FOUNDER OF THE CENTER FOR HEALTH TECHNOLOGY AND INNOVATION, "HEALTH CARE AND ECONOMIC ACTIVITY," 2001, 2001, 2001

### Why invest?

- Our nation's most valuable asset is human capital. Healthier citizens are the key to robust economic growth and greater productivity.
- The average American spends almost \$5,000 a year on health care. Less than \$20 of that amount is invested in research to prevent, treat and cure diseases and disabilities.\*
- Heart disease, stroke, cancer, diabetes and Alzheimer's disease alone cost an estimated \$771 billion in 2003.\*\*
- The average cost of caring for an Alzheimer's patient is \$5,000 a month. A delay in the onset and progression of Alzheimer's disease by five years could save \$50 billion a year in health care costs.\*\*\*
- Increased investment in science and innovation is required for our national security.

SOURCE: "HEALTH CARE AND ECONOMIC LIFE," TECHNOLOGICAL CHANGE AND ECONOMIC ACTIVITY, HEALTH CARE, 2001, 2001, 2001; NATIONAL INSTITUTE OF MEDICINE, NATIONAL RESEARCH AND DEVELOPMENT SURVEY, 2004; NATIONAL INSTITUTE OF MEDICINE, NATIONAL RESEARCH AND DEVELOPMENT SURVEY, 2004; NATIONAL INSTITUTE OF MEDICINE, NATIONAL RESEARCH AND DEVELOPMENT SURVEY, 2004

*"Public funding has expedited growth in the life sciences and catalyzed private interest in the sector."*

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[info@researchamerica.org](mailto:info@researchamerica.org)

**“Science can be sold  
to this  
Administration and  
this Congress. ...It is  
time now to have  
more affiliation with  
industry, because  
industry has more  
impact in the  
Congress.”**

~The Honorable Paul G. Rogers,  
chair, Research!America, at a AAAS  
post-election panel discussion on  
December 1, 2004.

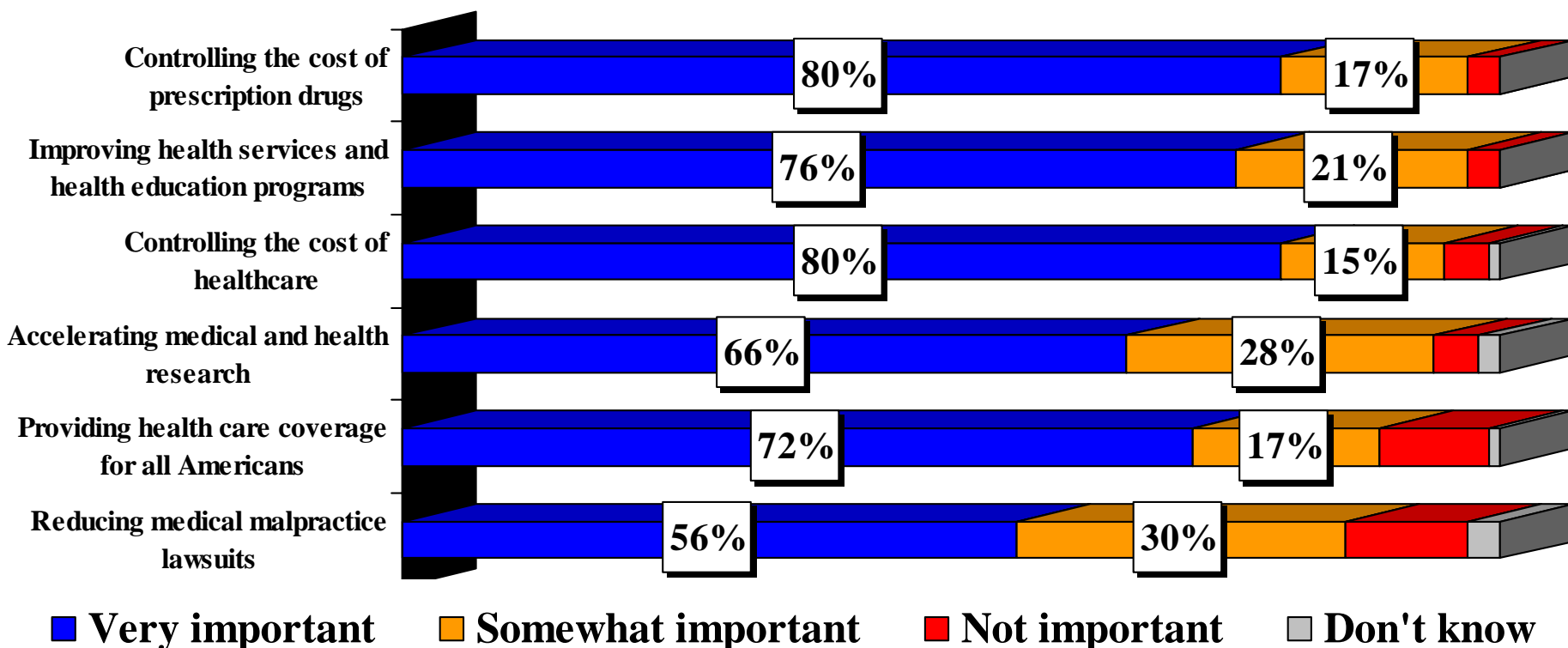


# How Research Saves Money:

- **Treatments that delay the onset and progression of Alzheimer's disease by five years could save \$50 billion a year in health care costs.**
- **Researchers have developed treatments that delay or prevent diabetic retinopathy, saving the U.S. \$1.6 billion a year.**
- **Preventing HIV transmission from an HIV-infected pregnant woman to her baby would save an estimated \$650,616 in medical costs and lost productivity over the child's lifetime.**

# Controlling Cost of Health Care Important to Americans

How important would you say each of the following health issues are in terms of national priorities?



Source: National Survey, 2005  
Charlton Research Company for Research!America

# Differing Priorities

## “The Public”

1. **Controlling the cost of health care ..... 80%**
2. **Controlling the cost of prescription drugs..... 80%**
3. **Improving health services and health education programs .....76%.**
4. **Providing health care coverage for all Americans .....72%**
5. **Accelerating medical and health research.....66%**
6. **Reducing medical malpractice lawsuits.....56%**

## “Leaders in Health Care Policy”

1. **Expanding health care coverage to the uninsured .....87%**
2. **Improving quality and safety of medical care, including increased use of information technology .....69%**
3. **Medicare reforms to ensure long-run solvency.....50%**
4. **Enacting reforms to moderate rising costs of medical care for the nation .....48%**
5. **Medicare payment reform.....38%**
6. **Controlling rising cost of prescription drugs .....35%**
7. **Addressing health disparities.....31%**
8. **Malpractice reform.....30%**

Sources: National Survey, 2005, Charlton Research Company for Research!America; Commonwealth Fund Health Care Opinion Leaders Survey, 2005.



**“You can change the image of things to come. But you can’t do it sitting on your hands...The science community should reach out to Congress and build bridges.”**

**~ The Honorable John Edward Porter, chair-elect, Research!America, at the AAAS/Research!America post-election forum on December 1, 2004.**

# In Conclusion...

The “new politics” of science demand:

- assuring that research is an *all-American* priority.
- rejecting the suggestion that we should lower our expectations.
- making the economic case for research.
- building new champions for research.
- remembering Tip O’Neill’s adage:  
“all politics is local.”
- putting a human face on research—Yours!

# Acknowledgements

**To my colleagues for their assistance and  
consultation on this presentation,  
thank you!**

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Stacie Propst, PhD  
Turna Ray  
Emily Thompson**



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